

Alzheimer's Association and Alzheimer's Impact Movement Statement for the Record

United States House Committee on Energy and Commerce, Health Subcommittee Hearing on "Are CDC's Priorities Restoring Public Trust and Improving the Health of the American People?"

July 23, 2024

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the United States House Committee on Energy and Commerce, Health Subcommittee legislative hearing on "Are CDC's Priorities Restoring Public Trust and Improving the Health of the American People?". The Association and AIM thank the Subcommittee for holding this hearing to consider issues important to the millions of people living with Alzheimer's and other dementia and their caregivers.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. Our mission is to eliminate Alzheimer's and other dementia through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. AIM is the Association's advocacy affiliate, working in a strategic partnership to make Alzheimer's a national priority. Together, the Alzheimer's Association and AIM advocate for policies to fight Alzheimer's disease, including increased investment in research, improved care and support, and the development of approaches to reduce the risk of developing dementia.

Millions of Americans living with dementia often face the challenge of navigating complex care landscapes without adequate support, leading to poorer health outcomes, high rates of hospitalization, and significant caregiver stress. According to the Alzheimer's Association's 2024 Facts and Figures and Special Report, nearly 7 million Americans are living with Alzheimer's. By 2050, that number will approach 13 million. Sixty percent of health care workers believe that the U.S. health care system is not effectively helping patients and their families navigate dementia care. A majority of caregivers (70 percent) report that coordinating care is stressful, and two in three (66 percent) have difficulty finding resources and support for their needs. Unfortunately, our work is only growing more urgent.

The BOLD Infrastructure for Alzheimer's Reauthorization Act (H.R. 7218/S. 3775) and the CDC

We are also grateful to Subcommittee Chairman Brett Guthrie and Committee member Congressman Paul Tonko for their leadership on the bipartisan 2018 Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406), and recent efforts to reauthorize this important law through the bipartisan BOLD Infrastructure for Alzheimer's Reauthorization ACt (H.R. 7218/S. 3775). The BOLD Act, funded by appropriated funds through the CDC, has enabled communities nationwide to implement public health strategies that promote brain health, increase early detection, address dementia, and support people living with dementia and their caregivers. The BOLD Act provides an avenue for the activation of advances in knowledge to be integrated into our public health infrastructure. Public health can integrate brain health messages into existing, relevant public health campaigns, acknowledging the growing evidence that healthy living can reduce the risk of cognitive decline and may reduce the risk of dementia. Public health can also undertake public awareness campaigns to promote

early detection and diagnosis, and can educate medical professionals about assessment tools, which is critical to ensuring access to treatment. Public health can also increase access to care and services by ensuring providers are trained in evidence-based care guidelines, and people living with dementia and their caregivers have the support and resources they need in their communities.

We also thank the CDC for prioritizing BOLD implementation in a way that benefits people living with Alzheimer's, and their caregivers and families. Since its enactment, the CDC has made 66 awards to 45 state, local, and tribal public health departments. These award recipients are working to implement public health strategies tailored to local populations as well as create, update, and operationalize state plans to address Alzheimer's disease. The CDC has also awarded funding to three Public Health Centers of Excellence each focusing on a priority public health area of need: dementia risk reduction, early detection of dementia, and dementia caregiving. Together, this infrastructure helps implement strategies from *The Healthy Brain Initiative: State and Local Road Map for Public Health* (HBI Road Map) and *Healthy Brain Initiative Road Map for Indian Country*, which provide a framework for BOLD award recipients to lead with urgency and act for impact in their communities to improve brain health across the life course and support caregivers.

The BOLD Act continues to make a significant impact on communities across the country. For example, in Kentucky, BOLD funding is increasing the state's capacity to operationalize its Kentucky State Alzheimer's Plan. Kentucky's initial investment in Alzheimer's disease and other dementia led to the creation of a full-time state agency Dementia Services Coordinator staff position which was a catalyst for their application to the BOLD Program award. In September 2023, the Kentucky Department for Public Health was awarded a BOLD Public Health Program Component 1 award to develop strategic statewide strategies to address Alzheimer's disease. This funding is already allowing the state to support the work of Kentucky's Office of Dementia Services.

Using the HBI Road Map, the state of Washington has expanded its public health infrastructure to increase the populations served and discuss dementia throughout the continuum of disease, from risk reduction to the late stages of the disease. For example, the Washington State Department of Health released guidance to local health departments on effective ways to use the HBI Road Map and conducted an internal agency evaluation to assess its ability and identify potential gaps in addressing Alzheimer's and caregiving needs. The state has also allocated funding to support the statewide expansion of dementia-specific public awareness efforts at the Memory and Brain Wellness Center at the University of Washington and to other state-led public awareness efforts aimed at reducing the stigma surrounding dementia as well as educating physicians about the importance of the early detection and diagnosis of Alzheimer's. This work led to the CDC awarding the Washington State Department of Health with the state's BOLD Public Health Program Component 2 award in September 2023, which will allow the state to expand upon these actions.

In September 2020, Wisconsin received a BOLD Public Health Program Component 1 award, and, through this grant, the Wisconsin Department of Health Services is utilizing existing public health infrastructure to increase early detection and diagnosis, reduce the risk of developing dementia, and support dementia caregiving. Wisconsin is in the process of implementing the Wisconsin State Dementia Plan: 2019–2023, its third state dementia plan. The current state plan has four areas of focus: care provided in communities where people live; improving how health care providers diagnose and care for people with dementia; responding to crises involving people with dementia; and care provided in assisted living, nursing homes, and other

residential facilities. Further, a steering committee, led by the Department of Health Services, was established to ensure the state plan is implemented with the assistance of four "leadership teams" (work groups) that are responsible for assisting the Steering Committee in each of the four focus areas: care in the communities, health care, crisis response, and facilities-based care. The CDC awarded Wisconsin with its second BOLD award in September 2023, which will allow the state to continue building upon the great progress made thanks to its first award in 2020.

California recognized its need for a comprehensive Alzheimer's public health infrastructure and used the resources provided by the federally funded Healthy Brain Initiative (HBI) as a framework to establish the California Healthy Brain Initiative. For this, six local health departments across the state produced action plans, and educational outreach materials and conducted 101 media campaigns for the public. Furthering implementation of the actions in the 2018 HBI Road Map, California appropriated funds to the state Medicaid program to establish Dementia Care Aware in 2021, a statewide program providing primary care providers with the information and tools needed to successfully administer cognitive health assessments and determine the appropriate next steps for the patients. In 2020, the County of Los Angeles received a BOLD Public Health Program Component 1 award, and in September 2023, the county received a BOLD Public Health Program Component 2 award to continue this work. The California State Department of Public Health received its first BOLD Public Health Program Award in September 2023, when the CDC awarded the state with a BOLD Public Health Program Component 2 award to amplify its existing efforts to address Alzheimer's disease.

The Vermont Department of Health received a BOLD Public Health Program Component 2 award from the CDC in September 2020, and, in September 2021, the department launched a virtual Project ECHO series to help build capacity for dementia diagnosis and care. Over 80 participants joined the first session of this monthly telementoring program run through the Area Health Education Center at the University of Vermont's (UVM) Larner College of Medicine. The Department of Health also offers monthly "Dementia Corner Consults" for primary care providers and their teams, led by the medical director of the UVM Memory Program. Additionally, in October 2021, the Vermont Department of Health published a data brief on Risk Factors for Subjective Cognitive Decline in Vermonters. The CDC awarded Vermont with its second BOLD award in September 2023, which will allow the state to continue building upon the great progress made thanks to its first award in 2020.

Underscoring the importance of a public health approach to addressing Alzheimer's and dementia in our communities, while New Jersey does not currently receive BOLD funding, the state is active in developing Alzheimer's public health initiatives. For example, the New Jersey Alzheimer's Disease Study Commission was established in 2011 to study the current and future impact and incidence of Alzheimer's within the state. The New Jersey Alzheimer's Disease Study Commission Report was published in August 2016 and examined services within the state to meet the needs of those affected by Alzheimer's. Most recently in 2023, the New Jersey Department of Health participated in a public health program called Data for Action, a project of the HBI designed to support the integration of data on brain health and caregiving into public health planning efforts. This has allowed the health department to produce state-specific data on risk factors for Alzheimer's and other dementia as well as identify links between cognitive changes and other chronic conditions and health behaviors. New Jersey now plans to use their work to educate members of the public and inform key decision-makers on how to advance public health action on brain health.

These are just a few of the many examples of the innovation stemming from Alzheimer's

investment across the country. BOLD has clearly led to great progress in building and strengthening the Alzheimer's public health infrastructure nationwide. However, this important program is set to expire this year. The bipartisan BOLD Infrastructure for Alzheimer's Reauthorization Act of 2024 (H.R. 7218/S. 3775), introduced by Subcommittee Chairman Brett Guthrie and Committee member Congressman Paul Tonko, would extend this important law until 2029 and authorize \$33 million annually for five years, to reflect the program's current appropriated level. In May, the BOLD Reauthorization Act passed out of this Committee It is vital that Congress passes this bill and continues to invest in a nationwide Alzheimer's public health response that will help further population-level improvements, achieve a higher quality of life for those living with the disease and their caregivers, and reduce associated costs.

Conclusion

The Alzheimer's Association and AIM appreciate the Subcommittee's steadfast support and commitment to advancing issues important to the millions of individuals living with Alzheimer's and other dementia, as well as their caregivers. We look forward to continuing to work with the Subcommittee and other members of Congress in a bipartisan way to reauthorize and extend these laws through the BOLD Infrastructure for Alzheimer's Reauthorization Act (H.R. 7218/S. 3775). It is important that this law be reauthorized and fully funded, so the CDC can continue to advance Alzheimer's public health infrastructure and reinforce Congress' sustained commitment to a strategic approach to combating Alzheimer's disease and supporting caregivers nationwide while enabling further strides in understanding, treating, and ultimately preventing Alzheimer's and other dementia. Doing so will provide much-needed hope for the millions of families affected by this devastating disease.